DOCUMENT RESUME

ED 324 869 EC 232 414

AUTHOR Kalyanpur, Maya; Rao, Shridevi S.
TITLE The Perspectives of Low-Income, Black Mothers of Children with Disabilities on Outreach Efforts.
PUB DATE Dec 89
NOTE 26p.; Paper presented at the Annual Conference of the Association for Persons with Severe Handicaps (16th, San Francisco, CA, December 7-9, 1989).
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Blacks; *Disabilities; Elementary Secondary Education; Interviews; Low Income Groups; Mothers; *Outreach Programs; *Parent Attitudes; Parent Education; *Parent School Relationship; Parent Teacher Cooperation; *Personal Autonomy; Qualitative Research; Special Education
IDENTIFIERS *Empowerment

ABSTRACT

Using a qualitative research approach, the researcher interviewed (over an 11-month period) four black, low-income mothers of children with disabilities concerning their perceptions of empowerment in interactions with professionals from an outreach agency attempting to increase family involvement in the special education process. In previous interactions with other professionals, three major aspects associated with unempowering relationships emerged: disrespect, a focus on deficits, and a discounting of differences in parenting styles. In contrast, the mothers perceived their interactions with the current outreach agency professional to be more empowering as efforts were made to build collaborative and supportive relationships, to understand their needs, and to respond to them. Contains 10 references. (Author/DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED324869

The Perspectives of Low-Income, Black Mothers of Children with Disabilities on Outreach Efforts

Maya Kalyanpur

Shridevi S. Rao

Division of Special Education and Rehabilitation

Syracuse University

Paper presented at the annual conference of
The Association for Persons with Severe Handicaps,
San Francisco, CA.

December, 1989

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Maya Kalyanpur

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC 233414

Abstract

Using a qualitative approach to research, four black, low-income mothers were interviewed extensively and their interactions with professionals from an outreach agency observed over a period of eleven months to develop an understanding of their perspective on empowerment. In their previous interactions with other professionals, three major aspects associated with unempowering relationships emerged: disrespect, a focus on deficits, and a discounting of differences in parenting styles. In contrast, they perceived their interactions with the outreach agency professional to be more empowering as efforts were made to build collaborative and supportive relationships, to understand their needs and respond to them. Suggestions for further empowerment of minority families are discussed.

The Perspectives of Low-Income, Black Mothers of Children with Disabilities on Outreach Efforts

Traditional interactions between professionals and parents operate within the model of "technical rationality", wherein professionals are respected for their expertise, and are expected to define the problem and provide the solution (Schon, 1983). This type of parent-professional relationship tends to vest all the power with the professional, while it undermines, even overlooks, the parent's possible contribution to defining the problem. As a result, parents of children with disabilities have had limited power in deciding the kinds of services and supports that they need (Cutler, 1981). In traditionally disenfranchised populations, like low income families, this problem of an unequal distribution of power is exacerbated (Cummins, 1986).

In recent years, there has been an effort to move away from this traditionally defined relationship toward a more equitable distribution of power and a relationship based on reciprocity and mutual respect (Wright, Saleeby, Watts & Lecca, 1983). Consonant with this trend, extension services have been launched that reach out to unserved or underserved populations (Agosta, O'Neal & Toubbeh, 1987; Flaskerud & Anh, 1988). The purpose of many outreach projects is to provide individualized, consumer-oriented services in an effort to empower the families hitherto disenfranchised. In most cases, these efforts have been in terms of involving or increasing the participation of the families in the special education decision-making process.

In this paper, we present the perspectives of four low-income, black mothers of children with disabilities on their relationship with professionals and their participation in the special education decision-making process. In particular, we observed their interactions with one agency that was attempting to develop an outreach model to increase the involvement of minority families in the special education process. The first part of the paper briefly describes the families we interviewed, followed by an analysis of the mothers' perceptions of their relationship with professionals other than from the outreach agency, interactions that appear to have aspects of a traditional, unempowering parent-professional relationship. The second part presents the mothers' perspectives on their relationship with the outreach agency professional, then offers suggestions for helping to develop the further empowerment of minority families.

Method

Using a qualitative approach to research, we interviewed extensively four black, low-income mothers and observed their interactions with professionals from an outreach agency over a period of eleven months to develop an understanding of their perspectives on empowerment. The need to understand the parents' perspectives and develop culturally-appropriate materials to increase their participation in the special education decision-making process were among the outreach agency's explicit objectives. Towards this purpose, a black professional was engaged to maintain on-going contact with the families and a concurrent qualitative study of the perspectives of the parents on the outreach efforts was conducted.

The study was qualitative in nature, reflecting the concern of Bogdan and Biklen (1982) that the researcher understand behavior from the subjects' own frame of reference. Two specific strategies that are representative techniques of qualitative research: participant observations and in-depth interviews (Bogdan & Biklen, 1982; Taylor & Bogdan, 1984), were used. Analysis of data was concurrent with collection using the method of constant comparison, that is, the study was inductive, seeking to formulate hypotheses which explain the perspectives and behaviors of the participants and how they relate to one another (Glaser & Strauss, 1967). The themes and generalizations that emerged provided an analysis of the dynamics of outreach to minority families and their perspectives on empowerment.

Participant observations recorded the interactions of parents and the outreach professionals during parent meetings, workshops and home visits. Open-ended interviews were conducted with four of the participating families and three professionals. The mothers had opportunities to meet professionals from the outreach agency at workshops and meetings, but their long-term, in-depth interaction revolved primarily around one professional, whom we shall call Marion. It was she who visited the homes of the mothers we interviewed, and maintained on-going contact with them.

Our introduction to each of the families took place during one of Marion's home visits through which we sat. This was followed up by individual interviews with the mothers. To gain an adequate understanding of their perspectives, each mother was interviewed several times over a period of eleven months, each interview lasting over an hour. All the interviews and the interactions between Marion

and the mothers were tape recorded and later transcribed. While most interviews took place in the mothers' homes, some were also conducted over the telephone. Fieldnotes were maintained on the agency meetings, the workshops we attended and the telephone conversations.

The respondents

All four women are black, low-income single parents ranging in age from 30 to 41 years. Patty lives with her mother and thirteen-year-old son, Dequan, in a black working class neighborhood close to the downtown section of town. Labeled mentally retarded, Dequan has been in special education programs since kindergarten and is now in an ungraded, self-contained class at a middle school. Patty has a high school diploma and works a minimum wage at a human services job. Linda and Annie dropped out of high school and now have three children each. Linda's seven-year-old son, Dwayne, is autistic and is fully mainstreamed into the first grade of a regular public school. Quentin, Annie's eleven-year-old son, having been held back in the fourth grade for two years, was in the process of being evaluated for a learning disability during our study. Rose has two sons of whom three-year-old John attends a preschool for children with behavior problems or emotional disturbance. Rose dropped out of nursing school when John, a premature baby, was put on a respirator. All names have been changed.

Linda, Annie and Rose are on public assistance and live in two-bedroom apartments of a low-income housing complex. The complex consists of several identical four-storeyed buildings, large, red brick, and flat roofed. There are no lawns, no garages, no flowers, no trees, nothing to prettify the surroundings and mitigate the poverty.

Tenants must pay a higher rent to live in buildings with elevators, but the elevators rarely work. Yet the stairs remain unswept and uncleaned, strewn with cigarette butts, scraps of paper, and balls of dust, and fetid with an overpowering stench of urine.

Findings and discussion

What did empowerment mean to the mothers we met? Even though none of them directly articulated the definition of empowerment, it was reflected in their perspectives on the relationship they had and would like to have with professionals, the nature of support that they would appreciate, and the quality of services that they would like their children to have. To the mothers, their interactions with other professionals appeared to have aspects of an unempowering parent-professional relationship. On the other hand, they perceived their empowerment primarily in terms of their relationship with Marion, the outreach professional.

In this section, we first describe the mothers' perceptions of their unempowering relationships. Then we present their perceptions of an empowering relationship in terms of their interactions with Marion.

Aspects of unempowering relationships

There were three major aspects associated with unempowering relationships. These aspects are disrespect, a focus on deficits, and a discounting of differences in parenting styles.

Disrespect.

The past relationships of the mothers with other professionals have not been encouraging. The professionals' lack of respect for their views and the absence of trust in their relationship figured as

the most prominent features of this experience. As one mother put it, "It is about treating you like a human being. Not treating you like you are a vacant chair out there. Like they're talking to you but you don't exist." The mothers complained that the professionals dismissed their questions and did not spend time explaining or giving them information. Families were rarely asked by other professionals for times that were convenient to them before the meetings were set up. They felt that no effort was made to accomodate to their needs or even to understand their concerns. Past experiences had left many mothers diffident about attending IEP, Phase II and other evaluation meetings. They often felt that their presence was token and their views were neither elicited nor valued.

"If you don't get respect, you won't give no respect," commented one mother. The professional indifference the mothers were shown made them respond disrespectfully in turn to the service providers in varied ways. Linda was assertive enough to "have no problems dealing with them." Her tone was confident as she defined clearly her views on what she thought was best for Dwayne. Marion asked her if she went to Dwayne's IEP meetings. Linda's response was immediate:

> "Yeah. I go to all of them."
> "Okay," said Marion, "do they explain everything to you clearly?"
> "Yes, they do. And if I don't like it, I speak up. And they'll stop and they'll look at me, and I'll just tell them, either I agree or don't. I'm the mother. I say, I know what's right for him. If I don't want it, he doesn't get it. They have to accept that. I've always been outspoken."

Patty, on the other hand, claims to have "never really complained or confronted" the school system because "I just figured they were the

teachers. They knew what they were doing. So it must be okay." Confrontation was difficult for her, she said, because "I may talk a lot but really, in a crowd of people, maybe sitting around a table of highly educated people, I always feel like some of my ifs or ands or buts is going to be in the wrong place" and so, at the only meeting she attended, she "didn't say anything. I just sort of looked at them all and thought, well, they are a little more educated than I am, apparently they know what they're doing. So I didn't really argue or say, well, I disagree."

In contrast to the others, Rose's reactions to professionals was one of scepticism. "It is not an evaluation, it is their opinion," was how she described an assessment report of John. Like Linda, there were times when Rose was assertive and stated her needs clearly. At other times, the repeated dismissal of her views by professionals led her to adopt more covert forms of resistance. Rather than verbally challenge the suggestions of the teachers in John's school, she refused to carry them out:

> "They wanted me to practice stair climbing with him. (People) urinate on those stairs. I am not going to have my baby climb those stairs and fall sick."

The mother recognized that their opinions are not heard because they do not speak the language of the professionals and the professionals will make no effort to try and understand their language. Anxious to do the best for their child, the women adopted different ways of reacting to the professionals' indifference.

The mother recognized that their opinions are not heard because they do not speak the language of the professionals and the

professionals will make no effort to try and understand their language. Anxious to do the best for their child, the women adopted different ways of reacting to the professionals' indifference.

Focus on deficits.

Most of the mothers were discontented with the quality of services their children were receiving. They felt the service system and the professionals involved tended to be too focused on the deficits of the children. Annie described her experiences with Quentin's teacher:

> "They call him a classroom clown, and he ain't learning nothing. They'll say, all he want to do is just come to school to act like a clown... They just don't have enough for him, they just push him to the side and, as they say, just put a label on him and say, that's the bad one, that's the nothing one, just don't pay him no attention or whatever."

Patty and Rose felt the same:

> "They just aren't giving (Dequan) a chance. They're giving him no reading. I believe that anybody can learn anything if you're given a chance. But they haven't given him a chance."
>
> "They are saying something is wrong with John, he might be retarded. For example, like his talk. They say he can't talk but he talks pretty good."

The mothers themselves, while accepting that their children were different and had certain needs, preferred to look at the strengths of the child and see them as children first and not in terms of their disability or label. "Give him a little credit," said Rose about her son, "he has just got a behavior problem. He reminds me of his father. His father was stubborn, too."

All that the mothers were asking was that their children be "given a little credit" for the things they could do, rather than a

label of "the nothing one" for the things they could not. At no point did they deny the needs of the child. This is how Patty described Dequan:

> "He's a little slow but I think he can learn anything if he was really taught it. Because anytime we explain something to him and tell him how to do work or something he usually do it real well. He's not a problem kid. No behavior problems, fighting, not getting along with people. He works really well with people.... I think some of his problem is that he's a little lazy by not being in a regular class with the regular kids doing regular studies. You can see that he's not a severely handicapped kid. Far as I'm concerned, he's just as normal as the rest of us around the house in everyday things!"

Linda spoke proudly of Dwayne's abilities:

> "He gets up in the morning, he does everything for himself. I don't have to do anything for him. He's always been like that, even when he had his defects. Well, not really defects. Well, when he was...," she groped for words.
> "Not as advanced as he is now," suggested Marion.
> "Yeah," said Linda, "he always did things for himself."

Rose's pride in John is apparent in her description of him:

> "He is three years old and if you give him a book upside down, he will turn it round the right way. He can tell you his foot and his leg. He knows the difference between his ears and his nose. He knows women wear earrings."

Their children were "stubborn", "lazy", and "slow", by the mothers' description, and not "mentally retarded" or "learning disabled" as the professionals tended to see them. When the focus was on abilities, not disabilities, they were "just as normal as the rest of us."

Discounting of differences.

For the mothers, there is a sense that their skills as parents are constantly being evaluated. Rose felt the psychologist who

assessed John was actually assessing her:

> "She is judging me. I met this lady once, one time and she judged me... She kept saying his environment is making him act like that I am his environment."
>
> "So what is she trying to say?"
>
> "That I am not a good mother or something."

"Being a good mother" meant being strict with their children. "They call it strictness, we call it loving," commented one mother.

The mothers acknowledged that there were differences in parenting styles. "A black person does not raise their kids like a white person," said Linda, "(White parents) are more easy-going with them." That wasn't good, she felt, because it didn't give them a sense of responsibility.

Spanking was one technique the mothers used to help their children grow up to be disciplined and responsible individuals. However, it is important to note that every mother took great pains to make a distinction between "beating up" and "spanking". The former was an abusive form of punishment, but an occasional spanking was permissible and a sign of good parenting. As Annie clarified:

> "Spanking is when you just hit them a few times and don't leave no bruises on that number. But when you just hit them and hit them hard and you leave scars and they swell up bad, that's not spanking."

All the mothers indulged in spanking to discipline their children, even if it were just as a last resort.

> "He spit on Lakesha the other night and I didn't know till she told me. And so she grabbed him and put her hands over his mouth and he didn't like that. And I told him, I said, Dwayne, see, you just can't do that. I said, I spank Dwayne. And he got home, I did, I spanked him." (Linda).

"Sometimes he be so hyper hyper, I have to spank him and send him to his room." (Annie).

To the mothers, this was what good parenting was about: inculcating a sense of responsibility in their children by disciplining them. For them, this was the clearest manifestation of their love and caring for their children. Living on the brink was a fact of daily life for the women, and there were no guarantees for a less precarious life for their children. They hoped that by bringing them up to be disciplined and responsible adults, their children would be better able to cope with the uncertainty of the future.

"They gonna have to come over hard times, they gonna have to learn to do without. They say, don't holler at him, don't spank him. I say, that is the way a lot of white kids grow up. If you sit down and be good, I'll buy you so-and-so. But that's not life. Because you gonna come over hard times." (Rose)

"White parents pamper (their children) all the time. That's because they're able to give them more," said Linda.

"What do you mean?"

"All you have to do is just look at the way the world is run and who it's run by. It's not run by black people. It's run by white people. That's why it's 'effed up', to be honest with you. They have the advantage over everybody and they don't care. They really don't care who's starving and what a black person needs except for them."

Yet, the families live in fear of their child being taken away from them by a child abuse prevention agency. Complaints can be lodged by anybody, including neighbours, a situation that is hardly conducive to engendering trust among the people within the community. Agencies are also guilty of this fault which does not endear them to their beneficiaries, and creates an atmosphere of distrust between parents and professionals.

It was this difference in perspective that gave rise to distrust

on both sides, particularly since, the mothers felt, the professionals did not recognize or value these differences. According to them, the most significant reason for the professionals discounting these differences in parenting styles was the fact that they are "white, have no children, and live in hundred, thousand dollar houses" and "don't know how to raise or deal with black people." How, they ask, can they understand the experiences of black, poor, single mothers?

> "You got bummy blacks and bummy whites. And you are saying, everybody black is stupid, and you are bums, and you are no good. That's not true. These are white people born with money. They are not struggling. They don't have a handicapped child in their house. I can't put on your shoes. I can't tell you what to do unless I wear your shoes."

When Dwayne was first identified as being autistic, the agency put Linda in touch with another parent to share her experiences as the mother of a child with severe disabilities. She thought it was a ridiculous idea:

> "She said, my son, he's in a normal high school. He's just like Dwayne. I looked at her and I said, what do you mean, he's just like Dwayne? I look at my color of skin..."

Patty explained why she felt that a difference in perspectives had led to Dequan's being labeled in school:

> "Dequan was just sort of church oriented and I think he went to school with some of his notions of church and so they say he's disabled, handicapped.... If you didn't really know anything about black culture and all their religion, you would get really frightened of some people in a church service. You'd think they're the most abnormal people you've ever seen in your life! And really they can be a highly educated person. But if you see them in church, you'll feel really different. So, I think, sometime people don't understand."

Underlying the conflict arising from the professionals'

persistent ignoring of the different parenting style of these black mothers is the dynamic of power. Though the mothers believed strongly in their own ability to raise their children, they were often deemed incompetent by the professional. Forced to confront their powerlessness in a system that gave credence to the service provider's opinions over theirs, the mothers began to resent, distrust, and resist the professionals.

Aspects of empowering relationships

In contrast to the relationships described above, Marion's interactions with the families indicate that professionals can develop a close relationship with parents. Marion is a black, middle-class professional. She is also the parent of a child with disabilities and two of her siblings are disabled. Marion brought to her interactions with the families not just her skills as a professional and her experience as a parent, but a set of values and attitudes. These attitudes were manifested through Marion's responsiveness to their needs and the rapport she was able to develop with them.

Responsiveness to needs.

The needs of the families can be diverse, varying from wanting to be accompanied to meetings to finding a placement for their child. Marion's responses to this range of needs were of two kinds: those that fell within the domain of affect in terms of being an emotional support to parents, and those that were action-oriented, of a more practical nature.

Being a support. Informing parents about their rights or providing explanations of different educational documents and

professional jargon was part of Marion's role. Even when she used simple language to explain technical concepts, Marion did not "talk down" to the women. She incorporated specific instructions into the flow of the conversation and maintained the same conversational style when giving explanations. She did not offer to undertake to do the tasks because, she said, she did not want them to become dependent on her. Instead, she explained the process involved in evaluating, labeling, and planning an educational program in very simple terms without using any jargon. Then she suggested what they could do to resolve the problem they were currently facing.

Patty was unhappy that Dequan was not learning any academics in school, merely functional skills that he demonstrated competence in at home. But she did not know what to do since his IEP for the current year had already been signed. Marion suggested that she call his teacher and let her know what Patty's concern was. Perhaps some changes could be made in the next IEP. This is how she explained the situation to Patty:

> "See, the law says that the child must have his individual educational plan, what we call the IEP, and that's what he's supposed to learn. You read the IEP and you say you want some changes. You want more academics. That's where your rights come in. That's where you step in and say, 'hey, let's try something else'. Call his teacher to set up an IEP meeting. The teacher writes the IEP. She may say that he needs to be evaluated before the meeting can be held. That's okay. You express your concerns. Tell her 'I want to have some academic subjects put into his IEP.' Tell her he knows how to use the toaster. He knows not to eat soap liquid. Tell her he doesn't need to learn to tie his shoelaces. I know plenty of kids nowadays who don't!"

Providing specific services. After the initial meetings organized by the schools and other agencies, Marion was swift to

follow through with home visits to inquire into the mothers' concerns. The mothers particularly appreciated the promptness with which Marion acted. For instance, within two weeks of her initial meeting with Rose, Marion procured a helmet for her three-year-old son to stop him from injuring himself when he banged his head. As Rose puts it,

> "I had been asking for a helmet since September, (but) no helmet, no helmet, no helmet. I met (Marion) for two weeks and she went and borrowed a helmet. It was too big but it was a helmet. I had been waiting since September but I got it in December. She came in the end of November and got me a helmet. Like in two weeks."

When the mothers asked Marion to accompany them and support them through the intricacies of the meetings, she agreed to do so. When Patty was asked how she thought Marion might be able to help change Dequan's IEP, she replied:

> "I had talked to her and she said she would go with me to the meeting. Have a little schedule when she would be able to help talk to them and speak up. So I'm sort of looking forward to that, depending on that."

Marion would explain the purpose of the meeting, outline the procedure, and suggest issues or questions that the mother might raise. During the course of a meeting with the psychologist, Marion's presence served as a good support for Rose. When the psychologist asked Rose questions on John's language skills, Marion corroborated Rose's observations:

> "Does he call you mom?" asked the psychologist.
> "Sometimes he does call me mom," replied Rose, "and when you give him a five, he says, too slow."
> "Yeah, he did that to me the other day," said Marion, "he probably learnt it from Rose's brother."

Marion arranged for Dwayne to go to an integrated after-school

program. She also procured a placement for John in a preschool program for children with emotional disturbance.

At the mothers' request, Marion organized a series of workshops on parenting. However, poor attendance at the workshops became a problem so Marion began to schedule the workshops on days other than when the mothers would have to stay at home to wait for their groceries to be delivered. She also changed the timings from late to early afternoon to better suit their daily routines.

Marion also began to send out reminders about forthcoming meetings and workshops. She felt that the mothers had so many other priorities that they found it difficult to keep track of the activities of the agency. A second reminder would be sent out two days before and a third on the morning of the workshop.

Recognizing that often families could not attend the workshops or meetings because they could neither leave their children behind at home nor take them along with them, Marion organized child care for them at the workshops and meetings. The mothers were informed ahead of time about the arrangements.

In addition, most of the families did not have cars, making it difficult to get to the workshops. The local public transportation system is neither cheap nor convenient for a mother with young children. So Marion would use her family van to pick up and drop off the mothers.

Marion was careful to set up appointments at times convenient to the mothers. Meetings were not scheduled on the first and sixteenth of the month, the two days on which the welfare checks arrive, bills are paid and groceries bought.

Responding to the immediate needs of the families required a certain flexibility. Marion defined her role and course of action according to the circumstances. Thus, in different situations, she was a support person, a driver, a babysitter, a secretary, a friend, somebody to count on and someone to turn to for help.

Establishing rapport.

One of the striking aspects of Marion's relationship with the mothers was rapport. Establishing rapport means not only having the ability to empathize with the experiences of families, it also involves the ability to actively create a common context. Marion created a common context by defining her relationship with the mothers as an interactive process based on a dialogue, where she and they came together to share their experiences and resources. She listened carefully to the mothers. She helped them realize that she understood their experiences and did not find them unfamiliar. Thus, Marion and the mothers bonded in their similar roles as parents and women rather than as parent and professional to create the elements of a supportive relationship.

Being conversational. The tone of the meetings was conversational. Marion might make a home visit with a specific agenda: to elicit the mother's concerns and to give information about available resources and possible avenues of action. Yet the mothers' daily struggles with rent, housing conditions, and welfare checks could not be ignored. Therefore, the conversation began with queries related to these issues. Marion was careful to identify priority issues and respond to them before bringing up issues that were

specifically related to the question of disability. Rose invariably began the conversation by talking about the problems she was having with the welfare officer or the housing authorities. Marion always listened intently to her and made suggestions. A mother might bring up a tangential issue; the diversion was allowed to develop and anecdotes were shared. On one occasion, Patty talked about her experiences holidaying in Chicago and Marion joined in. A little later, they discussed the recent death of a popular minister. When Annie complained of a constant pain in her foot, Marion recommended a particular orthopaedic clinic that would accept Medicaid. The conversation was then adroitly brought back to the main subject of the child's disability.

Interpreting. Listening also involved the skill of understanding and interpreting what the mothers said. For example, Rose's statement that she would send John off to her mother because she was concerned about his behavior was interpreted by previous service providers to mean that Rose did not care for John. However, Marion's interpretation of this situation was very different:

> "She will say, I am sick of the child. I need a way out. This is her way of saying, I need help. She wants help. She wants a program for John. This reaching out is misunderstood. They think she does not want John and that she does not have parenting skills. See, I see John banging his head. (But) I don't see her abusing him mentally or physically. They don't understand that."

Marion's ability to appreciate the underlying meaning behind Rose's words contributed towards building a trusting relationship with her.

Sharing. Rather than relating to the mothers as passive recipients of her services, Marion preferred to interact with them on a more reciprocal basis. She did not attempt to teach the mothers.

Instead, by sharing stories from her own experiences, she offered them strategies that worked for her. When Linda described how Dwayne embarrassed her in the grocery store by demanding to eat his favorite food before it was bought, Marion narrated her experience with her grandson:

> "I played a little game at getting him to help me. Get me half a gallon of milk. Good, you got me half a gallon of milk. Now go over and get me six loaves of bread. It becomes an educational thing, too. You're teaching them the measurements. You're teaching how to count. And it became a game with him, and he enjoyed that. So maybe that's one thing you could try with Dwayne."

When Rose mentioned that she was tired of John waking up in the night, Marion told her to be firm with him as she herself had been with her brother.

They are the stories of a mother who has faced similar crises, told to reassure the other mothers that they are not alone. With Patty, who was worrying about her impending hysterectomy, Marion talked of her sister who recently underwent similar surgery. When Annie worried that her son appeared to be slow in school, she told of the time her daughter was identified as being retarded.

> "I said, she's not retarded. I got really highly upset about that... I kept saying she was slow. I didn't know any better either. I just kept, yeah, she's slow. Yes, she's a little behind the other kids."

There were small details, like her clothes, to which Marion paid careful attention that further helped the mothers identify with her. Instead of the business suits that were reserved for meetings with other professionals, Marion preferred to be dressed in loose smocks, her face free of make-up, during home visits. At informal social

events, like the Halloween dinner, she wore a jogging suit. These were the outfits the mothers wore on a regular basis, and seeing Marion dressed in them made them feel she was one of them.

Accepting. Marion always made the mothers feel confident about their skills as parents. She would make it clear that they had the authority to decide how to bring up their children and that she trusted their judgment on how to do so. On one occasion, Rose spanked John when he began to act up. Marion's reaction to this was:

> "That's right. Discipline him, give him on his behind. You know (the researcher) and I are outsiders. We can't discipline and do what you can do as his mother. There's a difference between spanking your child and beating him up. You are not beating him and they can't take away your child. You tell them. Show them you can do it."

The mothers' affection for their children was not manifested through many physical gestures or words. Interspersed among directions to "go get some tissue, wipe your nose" or "you're not going down. I told you to wait," were terms of endearment like "snotty nose" and "you real hyper". During one interview, Dwayne stood at the table reiterating "want chicken". Since the chicken was too hot, he was asked to wait and, after a while, he began to pout. In response, Linda rubbed her hand over his pouting face and said, "you ugly."

An incident at Annie's house seems to bear out this tendency to minimize physical manifestations of affection. When her nephew cut his lip badly while playing, Annie did not run up to him. Instead, she continued to sit at the table and calmly asked the boy to come up to her. She gave him a piece of ice wrapped in a towel to hold to his lip that was by now horribly swollen and, without the slightest

outward display of sympathy for his condition, proceeded to ignore him for the rest of the interview. Yet, Annie is fond of her nephew. She often allowed him to clamber on to her lap as we talked. She would take him downstairs to play with the other children in the neighbourhood because he did not like going with his older cousins.

Marion let the mothers know that she understood how much they cared for their children by praising them when they described how they coped. Her response to Linda's story about Dwayne in the grocery store was one of encouragement:

> "I gave the lady back her Doritos," described Linda, "and took him out of the store."
> "How did he react to that?" asked Marion.
> "He calmed down."
> "That was making him responsible for his actions in the store," said Marion, "that was a good thought on your side."

A major aspect of the relationship between Marion and the mothers was the common experience of being black. Marion's recognition of the significance of color in the mothers' life experiences validated their anger against the professional indifference they encountered. It was so important to Marion herself that she often directed our own inquiry in that direction. She urged the mothers to talk about "cultural differences" when she introduced us to them. She saw issues they brought up in terms of color: lack of information about services, lack of access to services, assessment and placement, interactions with professionals.

> "She is a white lady and she does not have any kids. How can she come here and teach you about your son?"

The mothers appreciated this understanding and felt comfortable with

her. They knew she valued their perspective and by so doing, Marion gained credibility as a person they could trust.

Respecting and valuing the different parenting styles is a crucial step towards building a trusting and positive relationship with families. By recognising that being a professional did not give her the power to sit in judgment on the mothers for the various parenting techniques they used, Marion was able to get the mothers to trust her and become more actively involved in developing a reciprocal relationship.

Future directions

Often services provided to low-income, minority families are ineffectual because the families' needs and values are misunderstood or ignored. In this context, Marion's efforts to spend time with the families, getting to know them, building trusting relationships and learning their problems are extremely creditable. By recognising and accepting these differences in values, Marion validates the perspectives of the families, thus empowering them to a large extent. However, she can further empower the families she serves by representing their perspectives to others and helping others to become aware of what the differences are, and by not expecting the mothers to become "professionalized" in the process of learning to be advocates for their child.

Interpreting needs to the larger community.

Marion's new-found knowledge is crucial and her role must include becoming an advocate for the families by extending this knowledge to the larger community of professionals. On occasion, Marion has done

this. At an agency meeting attended only by professionals, Marion explained to the members how parents were often misunderstood:

> "Often when the mother doesn't attend the (IEP) meetings, the schools will say that parents aren't interested. They don't even think that maybe the parent isn't here because she can't be here. Maybe she doesn't have transportation, or she can't leave the kids at home... No one cares to think why I'm not coming. They just think, I'm not interested because I didn't come."

At another similar meeting, speaking of the minority mothers the agency was serving, she mentioned that "the disability is just a small part of their lives. They've got other, bigger worries, like SSI, paying the rent, furniture, food stamps."

One of the objectives of this project was to help the mothers develop better parenting skills. Towards this end, the agency conducted a series of workshops on behavior management of children with disabilities for the mothers at Crestwood, being careful to use culturally-appropriate materials. However, the mothers who attended the workshops were less concerned about the materials than about the values of the trainers. Having the power to choose to spank their child was so important to them that during the workshop on discipline one of the mothers stated:

> "My mother came up that night and she told me, they tell you different things that can work. And I said, I don't care. I just need to know: Do they allow spanking? Do they believe in spanking?"

Thus, for the workshop to be effective, the trainers too would have had to "believe in spanking". They may offer alternatives in non-aversive strategies but to have denounced spanking as a form of discipline would only have served to alienate the mothers. A

professional herself, it may not be easy for Marion to advocate differences in perspectives that are opposite to those held by the professional community. However, if services are to meet the true needs of the beneficiaries and empower them to the fullest extent, the part of an advocate must become an integral aspect of Marion's professional role and that of any service-provider working with low-income, minority families.

Exploring new alternatives.

Lack of knowledge about their and their child's rights and about the kinds of services and programs available makes it difficult for parents to identify and articulate their needs in ways that professionals can understand. This is where Marion steps in. Through her knowledge of parents' rights and service options, she guides the mothers through the special education maze. Yet, it is a delicate balance. While attempting to interpret on behalf of the families, Marion must be careful not to bring in her own assumptions of their needs. If existing service options are limited and the mothers object to a program because of its "deficit-focus", they should be helped to develop new and creative alternatives, instead of being told, "they have to learn that they can't say no. They must first take what they get and then ask for more."

Marion once asked Linda if Dwayne was on social security (SSI). Linda replied that he was not, because "I thought, maybe if they look at him now, they would deny him because he's come so far." Marion suggested that she try anyway by applying at the federal office through free legal services "because they would know exactly what the criteria are." A few months later, Dwayne began to receive an SSI

check. However, when asked if the extra money helped, Linda said:

> "Extra money? They cut my PA because of his SSI. I don't want to touch his SSI because that's his money, but it's hard for me to pay my bills if they're gonna cut my PA."

Were the programs that Marion arranged for Dwayne and John to attend what their mothers wanted for them? Both Rose and Linda were ambivalent.

John was placed in a segregated preschool program for children labeled emotionally disturbed. Even though John was not labeled, Marion was aware that "no child gets out of that program without being labeled emotionally disturbed." This was no small concern for Rose:

> "They want to label him retarded. But I did not want no label. It's the parent's fault if we get them labeled because we did not care and we let them do it. Once they label him, it stays for life. It is not going away so soon. Once John is labeled, he is labeled for ever."

But, from her previous experience, Rose knows that she is caught in the system and has no choice. When she refused the earlier program that John was offered and withdrew him, "everything stopped."

Linda wanted Dwayne to learn some "boy skills." Marion suggested an after school program that the agency offered. Linda agreed to apply and filled out the form that Marion brought with her on a home visit. Did she think the after school program would teach Dwayne "boy skills"? Linda replied:

> "I don't know. If he gets in (the after school program), fine. If he don't, it's no problem. We'll think of something to do. I can find a lot of things for him to do. Do a lot of football and basketball with him.... Just take a court right down there. I don't know too much about basketball but the boy down the hall is going to teach him."

Marion first met Annie at the discipline workshop and Annie told her that she had a child who was "slow". At her first home visit, Marion met Quentin and asked him several questions about his grade and reading levels, quickly deducing that "he's been held back twice." She immediately recommended an evaluation and explained what that was:

> "An evaluation is where they do a scale, and they test to see if he has a particular problem... So they do what they call a psychological evaluation to see if there's something blocking him. It could be his eyesight. It could be his hearing. He could have some problem where he doesn't see things and mix them up or something that stops him from reading... And it's good to catch it now, so he can get help, so he could outgrow it.... He would get an individual education plan. And to get... Okay, some of the labels are like, they mostly say learning disabled. Learning disabled just means that there's a particular problem that's stopping a person from catching up.... I would advise to have him evaluated."

Annie was concerned about Quentin. His teachers had complained that he was acting like "the classroom clown", so they "kept him back one year. He stayed back two years." But she didn't want him to get a label. She emphasised that Quentin was not in special education and that an evaluation would only result in his being pushed into a corner of his classroom, labeled "the nothing one". She was relieved that Quentin had since realized "that his clowning would get him nowhere. His attitude has changed a lot. He's doing a lot better than he was." Yet Annie was uneasy. They lived in a neighbourhood that had "a lot of gang fights, and drugs, and child abuse, lot of stuff like that." What she wanted was a "summer school program or something like that, like in the summer time" for Quentin because she thought:

> "it'd be better for him to do some kind of... do something in school, keep his mind occupied. Keep any kid out of trouble 'cos once they don't have nothing to do, they be round some other kids that be doing something they shouldn't be doing. Some will rub off

on them."

She had even asked his teacher "one time, and she told me no."

Studies on the overrepresentation of minority groups in special education indicate that the implications are serious when a black child is labeled (Heller, Holtzman, & Messick, 1982). This reality must be considered when professionals attempt to find programs for minority children. In the effort to provide quick solutions, professionals often interpret the families' needs in terms of what the system has to offer. However, what the system has to offer or what the professionals recommend might not be what the family considers beneficial for their child. Granted that service providers are constrained by the lack of a wide range of available options, in their role as ally and advocate of the families they must accept the challenge of empowering parents to find new ways of having their needs met.

De-professionalization of disability.

Helping the mothers become advocates for their child and thus facilitating their empowerment does not necessarily mean that the mothers have to be "professionalized." They need not learn the jargon of the profession nor subscribe to its belief system. Nor should they be denied access to services for not doing so.

Empowering a mother also means permitting her to describe her son as "stubborn" as Rose does, or "lazy" as Patty does, or "slow" as Annie does, rather than "mentally retarded". It means that if she prefers to use indigenous networks to look after her child, networks that do not emphasise the child's disability status, she should be encouraged to do so.

An objective of this project was to find a means by which participation of the families in the project could be sustained beyond its duration. The agency professionals envisioned this to be the development of a support group of the parents who would meet regularly to discuss issues of common interest pertaining to the disability of their child:

> "Ultimately, we hope to build a network within the minority community among the mothers so that the project doesn't end when we walk away. The plan is to try and network across agencies, and also within families, help families build networks."

It was hoped that by networking with each other, the mothers would be able to meet some of their own needs amongst themselves.

> "Like sometimes the mothers say they can't do anything because they can't leave the kids with anyone. So maybe helping them to get in touch with other mothers and working out a system where they share the responsibility of looking after each other's children and can do the things they want to."

However, agency efforts to build this group had not met with much success by the time the project had drawn to a close. It was felt that one reason for the lack of success was that disability was not a priority issue:

> "They're not going to do it for whatever reasons. It could be all those day-to-day dealings that they're facing. Most of them are so busy with other kids, with the doctor's appointment, with the housing problems, with the food stamp problem, with a drug-addict boyfriend or with their own drug problems, with their next pregnancy, you know. They're not going to take the time out to do that."

Our understanding of the situation was that not only was disability not a priority issue, but "disability" per se, as defined by professionals, was not an issue at all. For instance, at the

workshops on behavior management of children with disabilities, the topics that generated the most discussion were landlords and health insurance.

The mothers used naturally occurring networks within their community to deal with most of the problems they faced in regard to their children. Baby-sitters, usually a relative, took care of all their children, not just the child with disabilities ("My mother, she's always been the baby sitter. She sees that he gets up and gets off to school." "When they were out of school for a week, my mother picked them up for four days." "My brother is about the only one that I trust with John. He comes and spends the night or something when I need him.") If the school could not provide an adequate program, both Annie and Linda preferred that Quentin and Dwayne stay home like their other children and use the resources available within the housing complex ("If they couldn't find him a decent program, he'll be home with me. Which is no problem. I send him down to the pool. He even goes to the karate stuff right there"). The mothers liked to do things as a family. So they took all the children along with them, when the family went south for the holidays ("We took him with us to Mississippi"), to church ("We have always gone to church. It's just where we belong, so quite naturally, he just follows"), or even grocery shopping ("I normally take him wherever I go").

Merely having a child with a disability did not necessarily establish a common ground for families to come together. There were other priorities which were far more pressing. Concerns about neighbourhood issues like drugs or teenage gangs, exploitation and harassment by landlords, meeting expenses from meagre welfare checks

were more real and overwhelming than the issue of disability. Thus, to ask the families to come together on grounds that are not perceived as being common is to artificially create a common agenda. It also assumes the existence of an ambience of trust and security which, in fact, did not exist. On the other hand, the mothers had developed indigenous networks that utilized generic community and family supports.

Services for people with disabilities are changing. Traditional, segregated options are giving way to alternatives that utilize generic resources to support children with disabilities within the community (Taylor, Racino, Knoll, & Lutfiyya, 1987). Empowerment of minority families occurs when the strengths of the community are drawn on. In the case of these low income, black families, their strengths lie in the existence of naturally occurring networks and their use of community resources. Thus, their empowerment would mean drawing on and enhancing these support systems rather than creating artificial, segregating networks.

Conclusion

Perhaps the greatest challenge for a professional serving minority families lies in striking a balance between using limited existing services to meet the needs of the families without compromising their value differences. Empowerment is not just a list of strategies but a posture. One of the most important features of this posture is accepting the perspectives of the family as valid and real. With traditionally disenfranchised groups, there is a tendency to dismiss their opinions as trivial, over-demanding and not worth

considering. However, active participation of the families in the special education decision-making process can only occur if their values and their perception of their needs are recognized and respected. Empowerment signifies changing the role of a service provider from that of an expert to that of an ally or friend who enables families to articulate what they need.

References

Agosta, J., O'Neal, M. & Toubbeh, J. (Eds.) (1987). A path to peace of mind: Providing exemplary services to Navajo children with developmental disabilities and their families. Window Rock, AZ: Save the Children Federation, Navajo Nation Field Office.

Bogdan, R.C. & Biklen, S.K. (1982). Qualitative research for education: An introduction to theory and methods. Boston: Allyn & Bacon.

Cummins, J. (1986). Empowering minority students: A framework for intervention. Harvard Educational Review, 56, 18-26.

Cutler, B.C. (1981). Unraveling the special education maze: An action guide for parents. Champaign, IL: Research Press.

Flaskerud, J.H. & Anh, N.T. (1988). Mental health needs of Vietnamese refugees. Hospital and Community Psychiatry, 39 (4), 435-437.

Glaser, B. & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago, IL: Aldine.

Schon, D. A. (1983). The reflective practitioner: How professionals think in action. New York: Basic Books.

Taylor, S.J. & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. New York: John Wiley.

Taylor, S.J, Racino, J.A., Knoll, J.A., & Lutfiyya, Z. (1987). The non-restrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Wright, R., Saleeby, D., Watts, T. D., & Lecca, P. J. (1983). Transcultural perspectives in the human services: Organizational

issues and trends. Springfield, IL: Charles C. Thomas.